Report and Recommendations of the Universal Newborn Hearing, Screening, and Intervention Program Task Force

April 2006

Universal Newborn Hearing Screening Program
Family and Community Health Bureau
Health Policy and Services Division
Montana Department of Public Health and Human Services

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INTRODUCTION

Why newborn hearing screening, diagnosis and intervention?

The national Directors of Speech and Hearing Programs in State Health and Welfare Agencies report that in 2003, 1 child in 1,000 screened will have a hearing loss. In comparison, Montana averages only 1 per 10,000 births per year with the metabolic disorder PKU for which universal screening has been undertaken for decades.

The Maternal and Child Health Bureau of the Health Resources and Services Administration reports that approximately 1-3 infants per thousand births are born with significant hearing loss. There is clear evidence that the implementation of universal newborn hearing screening substantially lowers the age at which children with congenital permanent hearing loss are identified.

Children who are identified early and receive intensive early intervention by six months of age perform as much as 20-40 percentile points higher than children who do not receive such intervention on school related measures (reading, arithmetic, vocabulary, articulation, percent of the child's communication understood by non-family members, social adjustment and behavior).

http://mchb.hrsa.gov/programs/genetics/hearingscreen.htm

Montana's response

When the 2001 Legislature enacted the statewide universal newborn hearing screening, tracking, and intervention program (see Title 53, Chapter 19, Part 4, MCA in Appendix A), a Task Force was incorporated in the legislation to:

- advise the Department of Public Health and Human Services (DPHHS) on the collection and reporting of information from the screening hospitals and other sources; and
- (2) to provide recommendations to DPHHS, hospitals, other health care providers, and the public concerning a variety of topics:
 - a) Appropriate methodologies to be implemented for objective, physiologically-based screening of newborn infants;
 - b) The number of births sufficient to qualify a hospital or health care facility for exemption from screening and procedures for informing persons how to arrange for hearing screening outside of the hospital or health care facility; and
 - c) Guidelines for reporting and the means to ensure identified newborns infants receive referral and appropriate audiologic assessment, evaluation, and follow up services.

The current members of the Task Force and state agency support staff (see Appendix B), met over a period of five months to address those specific responsibilities and to make

recommendations for an appropriate continuum of hearing program services beginning at birth. Their work was facilitated by the Montana Consensus Council through provision of a professional facilitator and adoption of a "Universal Newborn Hearing Screening and Intervention Task Force Process Agreement" as a framework for accomplishing the Task Force's mandate. (See Appendix C)

Executive Summary

The level of commitment and expertise of the Task Force made it an ideal group to address the joint concerns of improving the continuum of services for hard of hearing and deaf children in Montana beginning at birth. The group included representatives of deaf adults and children, advocates, physicians, audiologists, hospitals, state and federal agencies.

The Task Force agreed to make decisions by consensus and to utilize a problem-solving model for working through issues. Subcommittees were formed early in the process to address the topics of tracking, screening, diagnostic evaluation, and intervention. The subcommittees worked diligently between scheduled meetings to develop draft recommendations and proposed Guideline revisions for review by the full Task Force.

The Task Force was assisted in their work by Sib Clack, DPHHS/Hearing Program, who served as a valuable resource to the group in providing data and information from other programs and conferences.

Kathy van Hook served as the group's facilitator and task monitor, providing meeting agendas, summaries, a draft framework for the Report and Recommendations and help working toward agreement on decisions and recommendations.

- There was early agreement by the Task Force that the "Recommended Guidelines for Hospitals/Birthing Facilities, Primary Care Physicians/Medical Home, and Audiologists" were outdated and that the expertise of the Task Force could productively be utilized in proposing revisions. The document was last updated in July 2002. The proposed revisions were provided to DPHHS as part of the Task Force's work.
- There was agreement of the subcommittees that the UNHSI Program needs a Coordinator with appropriate skills and abilities to provide the best service, education, and communication for the various stakeholders directly involved with hard of hearing and deaf children and their families and providers. The UNHSI Program will be directed by a minimum of 1 FTE coordinator, who has demonstrated knowledge of pediatric audiology, aural habilitation and language acquisition of the deaf and hard of hearing.
- The Task Force recommends the current law be amended during the 2007 legislative session to make newborn hearing screening and reporting mandatory for all Montana's hospitals providing obstetric services.

- Each subcommittee of the Task Force developed specific recommendations for service improvements that will result in a defined continuum of necessary services for deaf and hard of hearing children. The continuum will be publicized and known to all interested parties, and readily accessible. The Task Force is also concerned that all deaf and hard of hearing children are identified to be included in the service continuum.
- The UNHSI Task Force has completed its task as defined in section 53-19-403 Montana Code Annotated. The task force recognizes that a complete continuum of services from birth through adulthood for the deaf and hard of hearing is essential to the education, health and well being of this population. The task force therefore encourages all agencies and entities to continue to work together to take the next steps towards building and supporting a comprehensive system of services

The specific recommendations are presented in the following sections under Tracking, Screening, Diagnostic Evaluation, and Intervention.

The Task Force will make this Report available to DPHHS, hospitals, other health care providers, and the public. It will be available on the DPHHS website.

The Task Force believes these recommendations are critical and strongly encourages the Department and other involved agencies to implement these recommendations in the interest of providing a well coordinated continuum of services for hard of hearing and deaf children and their families.

TASK FORCE UNHSI OVERALL RECOMMENDATIONS

- 1. Change existing enabling legislation (Title 53, Chapter 19, Part 4, MCA) in the 2007 Legislative Session to make universal newborn hearing screening mandatory by all hospitals providing obstetric services and to require all other health care providers and health care facilities to provide education to parents about the importance of newborn hearing screening and how to obtain it.
- 2. Promulgate Administrative Rules in DPHHS, MSDB and OPI to implement the revised legislation and the recommendations made by the Task Force.
- 3. The Universal Newborn Hearing Screening and Intervention (UNHSI) program will be directed by a minimum of 1.0 FTE coordinator who has demonstrated knowledge of pediatric audiology, aural habilitation and language acquisition of the deaf and hard of hearing. The UNHSI Coordinator will:
 - a. Ensure the maintenance and management of database information to ensure accomplishment of the 1-3-6 standard for UNHSI;
 - b. Keep records of infants lost to follow-up for re-screening and the referral process for intervention;

- c. Develop and implement public awareness materials for families, primary care physicians and other professional in the baby's medical home
- d. Collaborate with Part C of IDEA, the Montana School for the Deaf and Blind (MSDB) and the Office of Public Instruction (OPI) in the development of personnel training for early intervention service providers, personnel conducting hospital screening and follow-up screening of infants.
- 4. The UNHSI program will establish an advisory committee similar to the UNHSI Task Force which will serve in an advisory capacity to the DPHHS on issues related to the UNHSI program. The committee will meet no less than twice each year.
- 5. Implement a web-based state central database for the UNHSI program to incorporate screening, diagnosis and intervention services provided by DPHHS (including the Part C of IDEA program), MSDB, and other service providers, with links to OPI.
- 6. Update the Recommended Guidelines for Hospitals/Birthing Facilities, Primary Care Physicians/Medical Home, and Audiologists as recommended by the Task Force.
- 7. The UNHSI Task Force has completed its task as defined in section 53-19-403 Montana Code Annotated. The task force recognizes that a complete continuum of services from birth through adulthood for the deaf and hard of hearing is essential to the education, health and well being of this population. The task force therefore encourages all agencies and entities to continue to work together to take the next steps towards building and supporting a comprehensive system of services.

Tracking Component:

There are two fundamental responsibilities in tracking the newborn hearing screening, diagnosis and intervention components of a comprehensive service system for deaf and hard of hearing children in order to achieve the 1-3-6 standard of service: screening completed by one month of age; diagnosis by three months of age; and intervention by six months of age.

The first responsibility of the continuum is assurance that all babies born in Montana complete their hearing screening by one month of age. This represents a **population-based** component and involves linking birth records with screening records. This part of the continuum involves birthing facilities and external screeners who work with hospitals, parents, and primary care providers to ensure completion of newborn screening and referral for audiologic evaluation to qualified audiologists when newborn screening indicates a need for further evaluation to specifically diagnose hearing loss.

The second responsibility of tracking in a comprehensive system involves tracking the services provided to each child diagnosed as deaf or hard of hearing. This is a **service-based** component. This part of the continuum involves families,

primary care providers, the Montana School for the Deaf and Blind, the Office of Public Instruction, and service providers in accordance with the child's intervention plan.

Specific tracking recommendations include:

- An integrated statewide electronic data system is essential to effectively and
 efficiently provide accurate information about the screening status of all babies
 born in Montana and to document appropriate services for all children diagnosed
 as deaf or hard of hearing. Explore options for a web application or other
 technology to facilitate tracking and reporting.
- 2) Identify funding to support data management activities including:
 - (a) maintenance and enhancement of state level population-based and service-based databases at DPHHS, MSDB and OPI; and
 - (b) staff needed for data entry, quality assurance, monitoring and reporting at each involved agency.
- 3) Provide funding for electronic tracking and linking of Part C intervention services with other programs providing services to the deaf and hard of hearing population, including MSDB and Regional Pediatric Specialty Clinics.

Screening Recommendations

A two-stage newborn hearing screening process will be implemented by all Montana hospitals providing obstetric services. The process will ensure all newborns are screened for potential hearing loss and to identify newborns who need further diagnostic testing by no later than one month of age.

Stage 1 screening: All newborns are screened for hearing before discharge from the hospital after birth. Newborns who do not pass the initial (Stage 1) screening before discharge are scheduled for repeat (Stage 2) screening.

Stage 2 screening to determine need for further audiologic evaluation will be done by one month of age. The discharging hospital is responsible for ensuring the stage 2 screening appointment is made before discharge of babies who do not pass Stage 1 screening. Reporting of screening results to the state database is the responsibility of the discharging Montana hospital.

In the event of transfer, the final Montana discharging hospital is responsible for reporting and tracking of hearing screening of the newborn (i.e., if transferred out of state, the last Montana hospital from which the newborn is transferred is the responsible facility).

All Montana hospitals caring for newborns will work with the state UNHSI Coordinator in implementation of the hearing screening process

Test results and follow up for infants who do not pass Stage 1 screening will be disseminated to the primary care provider/medical home as well as to the state database.

Diagnostic Evaluation Recommendations

- 1. Licensed audiologists who have experience evaluating hearing in infants will conduct diagnostic evaluations on infants who do not pass hearing screening.
- 2. A licensed audiologist performing an infant diagnostic evaluation will have the testing equipment necessary to perform a comprehensive evaluation. At a minimum this will include equipment to conduct otoscopy, multiple frequency immittance audiometry, evoked otoacoustic emissions, auditory brainstem response testing with air and bone conducted click and tone-burst stimuli, and visual reinforcement audiometry.
- 3. Infants will obtain an audiologic diagnostic evaluation after abnormal newborn two-step hearing screening results or when recommended by a physician due to the baby falling into a high-risk category.
- 4. Audiologic diagnostic evaluation will occur within three months of birth, unless prohibited by extenuating medical circumstances
- 5. Test results and recommendations will be disseminated to the primary care provider/medical home, and to the Montana School for the Deaf and Blind for further tracking purposes.
- 6. Amplification will be implemented in accordance with current American Academy of Audiologists pediatric amplification guidelines.

Intervention Recommendations

- A. Intervention will be initiated by no later than six months of age for each child diagnosed as deaf or hard of hearing.
- B. The parental consent form for infant diagnostic screening will specifically request permission for data entry into the state database and referral to the Montana School for the Deaf and Blind (MSDB) for consideration of early intervention services, should the infant receive either a conclusive diagnosis of a hearing loss, or an inconclusive diagnosis leading to **presumptive eligibility** for intervention services.
- C. Parents must be presented with the opportunity for MSDB to make a referral to Part C. Part C must make a referral to MSDB when a child presents a diagnosed hearing loss.
- D. The early intervention program for deaf or hard-of-hearing infants and toddlers diagnosed with a hearing loss, or referred by a medical practitioner, or presumed

eligible for referral to MSDB, shall contain the following elements:

- 1. A qualified intervention case manager. A qualified intervention case manager is defined as a credentialed teacher of the deaf; an audiologist, or speech/language pathologist who has training in the area of language acquisition of the deaf and hard-of-hearing and has demonstrated extensive experience working with deaf and hard-of-hearing children; or an individual, identified by MSDB, who has completed a course of study in the area of language acquisition of the deaf and hard-of-hearing and demonstrated experience in working with deaf and hard-of-hearing children.
- 2. Comprehensive communication assessment, within 30 days of referral for intervention, by a provider qualified to administer and interpret results of the assessment.
- 3. An Intervention Plan initiated by MSDB and coordinated with a Part C plan if present, which identifies consultative and direct services to be provided by qualified service providers. The development of the intervention plan must include the participation of a professional with documented training and experience in the area of the acquisition of language of deaf infants and preschoolers. The intervention plan will be provided to the primary care provider.
- 4. Providers of services identified in the Intervention Plan who have a standardized knowledge base and skill set acquired through a structured program of professional development that has been reviewed and approved by representatives of Part C, MSDB, OPI, and the UNHSI Coordinator, as appropriate.
- 5. Family Advisors/Family Support Specialists will utilize a standardized curriculum for providing information to families served through the early intervention program. As determined appropriate by the Intervention Plan Team, the curriculum may consist of the following components:
 - i. A Communication assessment
 - ii. Information addressing the implications of deafness on language acquisition and developmental milestones for language acquisition
 - iii. Knowledge of, and a list of the specialists that provide services and information to families of deaf and hard-of-hearing infants and toddlers; pediatric audiologists, otolaryngologists, speech/language pathologists, educators of the deaf, interpreters, dispensing audiologists, and deaf mentors
 - iv. Communication modalities including: oral/aural, manually coded English, American Sign Language, Total Communication

- v. Amplification technologies, including cochlear implants
- vi. Aural rehabilitation and speech therapy
- vii. Family based methodologies for developing communication and language with deaf and hard-of-hearing infants and toddlers
- viii. Deaf culture
- ix. Educational services and placement options available for deaf and hard-of-hearing children at each stage of life: Age 0-2 (Part C, community-based) Age 3 through 18, Free appropriate public education (FAPE) provided by the public schools to the child if the child is determined IDEA eligible. Depending on school policy, FAPE may be provided to ages 19-21.
- x. All information provided will be current, accurate and unbiased
- 6. When the public school develops an IEP for an IDEA eligible student with deafness, a teacher of the deaf or otherwise knowledgeable individual must be invited by the public school to participate in the development of the IEP.
- E. MSDB has responsibility to assure appropriate intervention services by 6 months of age.

APPENDIX A -

TITLE 53. SOCIAL SERVICES AND INSTITUTIONS CHAPTER 19. PHYSICALLY DISABLED

Part 4. Newborn Hearing Screening

53-19-401. Purpose.

53-19-402. Statewide universal newborn hearing screening, tracking, and intervention program.

53-19-403. Task force.

53-19-404. Required education -- screening.

53-19-401. Purpose. The purposes of this part are:

- (1) to provide early detection of hearing loss in newborn infants as soon after birth as possible to enable children, their families, and primary health care providers to obtain any necessary multidisciplinary evaluation, audiologic assessment, treatment, and intervention services at the earliest opportunity and to prevent or mitigate the developmental delays and academic failures associated with late identification of hearing loss; and
- (2) to provide the state with the necessary information to effectively plan, establish, and evaluate a comprehensive system of appropriate services for newborn infants who have a hearing loss or who are deaf.

History: En. Sec. 1, Ch. 250, L. 2001.

53-19-402. Statewide universal newborn hearing screening, tracking, and intervention program. (1) There is a universal newborn hearing screening program in the department of public health and human services. The department shall implement the program to encourage a hearing screening test for all newborn infants to undergo for identification of newborn infant hearing loss. The department shall encourage newborn infant hearing tests to be completed before discharge from a hospital or no later than 3 months after birth.

- (2) The department shall adopt rules to:
- (a) determine the volume of births that would allow a hospital or health care facility to be exempt from providing newborn infant hearing screenings onsite before discharge;
- (b) develop information for and procedures by which health care providers, local health departments, health care clinics, school districts, and other appropriate resources may promote the importance of the screening of newborn infants' hearing and provide information regarding locations where screenings may be accessed for those newborn infants either not born in a hospital or who do not receive a screening in a hospital; and
- (c) determine any additional reporting requirements that are related to newborn infant hearing screening, evaluation, audiologic assessment, treatment, and intervention services.
- (3) The department shall assist hospitals in developing systems for reporting and in accessing funds to purchase hearing screening equipment by providing information on funding sources known to the department.

(4) The department may accept contributions, gifts, grants, or endowments from public or private sources for the use and benefit of this program.

History: En. Sec. 2, Ch. 250, L. 2001.

- **53-19-403. Task force.** (1) There is a task force on hearing loss in newborn infants for the purpose of advising the department of public health and human services on the collection and reporting of information from the hospitals and other sources and providing recommendations to the department, hospitals, other health care providers, and the public concerning but not limited to:
- (a) appropriate methodologies to be implemented for hearing screening of newborn infants that must be objective and physiologically based;
- (b) the number of births sufficient to qualify a hospital or health care facility for exemption from screening and procedures to inform persons how to arrange for hearing screening outside of the hospital or health care facility; and
- (c) guidelines for reporting and the means to ensure that identified newborn infants receive referral and appropriate audiologic assessment, evaluation, and followup services.
- (2) The task force may consist of at least 7 and not more than 12 members who must be appointed by the department director and must include the coordinator of part C services pursuant to the Individuals with Disabilities Education Act, 20 U.S.C. 1437, and a representative of a parenting organization. Members appointed to the task force must have training, experience, or interest in the area of hearing conditions in children. The members of the task force may be compensated as provided in <u>2-18-501</u> through <u>2-18-503</u> as funds allow.

History: En. Sec. 3, Ch. 250, L. 2001

- **53-19-404. Required education -- screening.** (1) Each licensed hospital, health care facility, or health care provider that provides obstetric services shall provide education to parents of infants born in the hospital or health care facility of the importance of screening the hearing of newborn infants and followup care. Education is not considered a substitute for the hearing screening.
- (2) Every licensed hospital, health care facility, or health care provider that provides obstetric services shall report quarterly to the department of public health and human services and to the task force the following information and any other information required by rule:
 - (a) the number of infants born in the hospital;
 - (b) the number of infants screened;
 - (c) the number of infants who passed the screening, if administered;
 - (d) the number of infants who did not pass the screening, if administered;
 - (e) the number of infants who received followup care; and
 - (f) the number of infants with hearing impairment.

History: En. Sec. 4, Ch. 250, L. 2001.

TITLE 53. SOCIAL SERVICES AND INSTITUTIONS CHAPTER 19. PHYSICALLY DISABLED

Part 4. Newborn Hearing Screening

53-19-401. Purpose.

53-19-402. Statewide universal newborn hearing screening, tracking, and intervention program.

53-19-403. Task force.

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- (2) to provide the state with the necessary information to effectively plan, establish, and evaluate a comprehensive system of appropriate services for newborn infants who have a hearing loss or who are deaf.

History: En. Sec. 1, Ch. 250, L. 2001.

53-19-402. Statewide universal newborn hearing screening, tracking, and

intervention program. (1) There is a universal newborn hearing screening program in the department of public health and human services. The department shall implement the program to encourage a hearing screening test for all newborn infants to undergo for identification of newborn infant hearing loss. The department shall encourage newborn infant hearing tests to be completed before discharge from a hospital or no later than 3 months after birth.

- (2) The department shall adopt rules to:
- (a) determine the volume of births that would allow a hospital or health care facility to be exempt from providing newborn infant hearing screenings onsite before discharge;
- (b) develop information for and procedures by which health care providers, local health departments, health care clinics, school districts, and other appropriate resources may promote the importance of the screening of newborn infants' hearing and provide information regarding locations where screenings may be accessed for those newborn infants either not born in a hospital or who do not receive a screening in a hospital; and
- (c) determine any additional reporting requirements that are related to newborn infant hearing screening, evaluation, audiologic assessment, treatment, and intervention services.
- (3) The department shall assist hospitals in developing systems for reporting and in accessing funds to purchase hearing screening equipment by providing information on funding sources known to the department.
- (4) The department may accept contributions, gifts, grants, or endowments from public or private sources for the use and benefit of this program.

History: En. Sec. 2, Ch. 250, L. 2001.

- **53-19-403.** Task force. (1) There is a task force on hearing loss in newborn infants for the purpose of advising the department of public health and human services on the collection and reporting of information from the hospitals and other sources and providing recommendations to the department, hospitals, other health care providers, and the public concerning but not limited to:
- (a) appropriate methodologies to be implemented for hearing screening of newborn infants that must be objective and physiologically based;
- (b) the number of births sufficient to qualify a hospital or health care facility for exemption from screening and procedures to inform persons how to arrange for hearing screening outside of the hospital or health care facility; and
- (c) guidelines for reporting and the means to ensure that identified newborn infants receive referral and appropriate audiologic assessment, evaluation, and followup services.
- (2) The task force may consist of at least 7 and not more than 12 members who must be appointed by the department director and must include the coordinator of part C services pursuant to the Individuals with Disabilities Education Act, 20 U.S.C. 1437, and a representative of a parenting organization. Members appointed to the task force must have training, experience, or interest in the area of hearing conditions in children. The members of the task force may be compensated as provided in <u>2-18-501</u> through <u>2-18-503</u> as funds allow.

History: En. Sec. 3, Ch. 250, L. 2001

- **53-19-404. Required education -- screening.** (1) Each licensed hospital, health care facility, or health care provider that provides obstetric services shall provide education to parents of infants born in the hospital or health care facility of the importance of screening the hearing of newborn infants and followup care. Education is not considered a substitute for the hearing screening.
- (2) Every licensed hospital, health care facility, or health care provider that provides obstetric services shall report quarterly to the department of public health and human services and to the task force the following information and any other information required by rule:
 - (a) the number of infants born in the hospital;
 - (b) the number of infants screened;
 - (c) the number of infants who passed the screening, if administered;
 - (d) the number of infants who did not pass the screening, if administered;
 - (e) the number of infants who received followup care; and
 - (f) the number of infants with hearing impairment.

History: En. Sec. 4, Ch. 250, L. 2001.

APPENDIX B

UNHSI Task Force members participating in Facilitated meetings December, 2005

Members (limited by law to 12)

Name	Representing	City	Phone	e-mail
Betty Van Tighem	Deaf adults	Great Falls	761-0769	vantighembe@bresnan.net
Cleo Klepzig	Parent of deaf child	Helena	227-8927	Cleokc77@aol.com
Evelyn Rider, MD	Neonatologists	Great Falls	452-6678	eridermd@bresnan.net
Laura Nicholson, MD	Pediatricians (AAP)	Billings	238-6600	bigskymind1@msn.com
Vicki Strohmayer	Hospitals	Miles City	233-4229	vicki.strohmayer@hrh-mt.org
Doug Baldwin	Audiologists	Billings	238-5000	dbaldwin@billingsclinic.org
Kristen Kober	Audiologists I.H.S.	Billings	247-7112	kristen.kober@mail.ihs.gov
Marilyn Pearson	OPI	Helena	444-4428	mpearson@mt.gov
MaryLynn Donnelly for Jackie Forba	Title V CSHCN*	Helena	444-3620	mdonnelly@mt.gov
Erica Swanson	Part C of IDEA	Helena	444-5647	epeterson2@mt.gov
Steve Gettel in place of Sandy McGennis	MSDB	Great Falls	771-6001	sgettel@msdb.mt.gov
Melissa Ann Hansen	Parents, Let's Unite for Kids	Butte	498-3483	mhansen@pluk.org

Consultants (non-voting)

Name	Representing	City	Phone	e-mail
Kitty Griffin	Speech Language Path.	Dillon	683-5806	cgriffin@barretthospital.org
Lynne Koester, PhD	U of M, Developmental Psych	Missoula	243-4003	lynne.koester@mso.umt.edu
Casey Blumenthal	Montana Hospital Assn	Helena	442-1911	casey@mtha.org
Sib Clack	DPHHS/Hearing Program	Helena	444-1216	sclack@mt.gov
BJ Archambault	DPHHS/CSHCN*	Helena	444-0984	barchambault@mt.gov
Frank Malek (as needed only)	DPHHS/Medicaid	Helena	444-4068	fmalek@mt.gov

^{*} Children with Special Health Care Needs (CSHCN)

APPENDIX C

Universal Newborn Hearing Screening and Intervention Task Force

Process Agreement: December, 2005

A **process agreement** clarifies group procedures for conducting meetings, reporting results, resolving differences, decision making as a group, and accomplishing the task of the group.

Upon adoption (see decision making in section 9.0), all participants in the Task Force agree to use this agreement to guide their collaborative work. This agreement may be amended by consensus of the Task Force as the work moves forward.

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1.0 What's the Policy Problem Montana is Trying to Solve?

(Primarily excerpted from Title 53-19-401)

Purpose. The purposes of this part are:

- (1) to provide early detection of hearing loss in newborn infants as soon after birth as possible to enable children, their families, and primary health care providers to obtain any necessary multidisciplinary evaluation, audiologic assessment, treatment, and intervention services at the earliest opportunity and to prevent or mitigate the developmental delays and academic failures associated with late identification of hearing loss; and
- (2) to provide the state with the necessary information to effectively plan, establish, and evaluate a comprehensive system of appropriate services for newborn infants who have a hearing loss or who are deaf.

2.0 Purpose Statement: How Can This Task Force Help?

According to Title 53-19-403 **Task force.** (1) There is a task force on hearing loss in newborn infants for the purpose of advising the department of public health and human services on the collection and reporting of information from the hospitals and other sources and providing recommendations to the department, hospitals, other health care providers, and the public concerning but not limited to:

- (a) appropriate methodologies to be implemented for hearing screening of newborn infants that must be objective and physiologically based;
- (b) the number of births sufficient to qualify a hospital or health care facility for exemption from screening and procedures to inform persons how to arrange for hearing screening outside of the hospital or health care facility; and
- (c) guidelines for reporting and the means to ensure that identified newborn infants receive referral and appropriate audiologic assessment, evaluation, and followup services.
- (2) The task force may consist of at least 7 and not more than 12 members who must be appointed by the department director and must include the coordinator of part C services pursuant to the Individuals with Disabilities Education Act, 20 U.S.C. 1437, and a representative of a parenting organization. Members appointed to the task force must have training, experience, or interest in the area of hearing conditions in children. The members of the task force may be compensated as provided in <u>2-18-501</u> through <u>2-18-503</u> as funds allow.

3.0 Task Force Work Plan

DATE	ACTIVITIES (subject to	Preparation Needed	OUTCOME(S)
	change)		
November 2005	Organizational meeting to adopt a process agreement. Determine and prioritize issues that the Task Force will problem-solve to develop recommendations to the department, hospitals, other health care providers, and the public.	Draft process agreement for review.	Process agreement reached by consensus, work plan discussed and adopted.
December 14, 2005	Consider reports from subcommittees on the tasks set in the first two meetings. Set next round of tasks.	Subcommittees meet	Discussion of subcommittee progress
January 4, 2006	Subcommittee reports, begin discussion on intervention. Set next round of tasks.	Subcommittees prepare first drafts	Work toward agreement on draft recommendations.
January 26, 2006	Report from screening subcommittee. Set the next round of tasks.	Screening & intervention subcommittee meet and prepare draft recommendations	Review draft recommendations and work toward agreement
February 15, 2006	Finalize recommendations.	Subcommittees meet and revise recommendations	Review draft recommendations and work toward agreement
March 15, 2006 - Helena	Finalize recommendations in report form for distribution.	Draft report prepared and distributed to Task Force members & consultants	Distribute final report and put on website.

4.0 Members

1. Twelve people have been appointed to the task force by the department director and include the coordinator of Part C services and a representative of a parenting organization (PLUK). (See Appendix A for a listing of the Task Force members)

5.0 Responsibilities of Task Force Members

- 1. Members will attend meetings or provide input pertinent to items for discussion if a meeting is missed. Decisions will be made by the members present as long as a quorum is present and an opportunity to provide input has been provided to members who are not able to attend.
- 2. Proxy voting will not be utilized.
- 3. Members will represent their constituency and keep them informed of issues being discussed, solicit input, and inform constituents of decisions made at meetings.

6.0 Consultants

1. The Task Force will consult individuals with specialized knowledge and expertise as needed or appropriate.

7.0 Time Frame for Task Force Work/Progress Needed

- 1. The Task Force members will jointly evaluate whether or not they are making acceptable progress by completing evaluation forms at the end of each meeting and submitting them to the facilitator.
- 2. At the end of each meeting the goals for the next meeting will be set based on the accomplishments and decisions made.

8.0 Meetings

- 1. The full task force will meet a minimum of four times (or more by agreement of the Task Force). At the first organizational meeting, dates will be set by the group. Information will be provided 5 7 days prior to each meeting to support informed discussion. Members and other invited sources will assist in bringing relevant information to the table. The Task Force can decide if information presented during a meeting will be addressed.
- 2. Focused task groups or subcommittees may be formed as the task force finds appropriate to conduct voluntary work to support the purpose of the group.

9.0 Communication and Group Decision Making

- 1. Members enter into dialogue with the intent to network and learn one another's points of view.
- 2. Meetings are for development of discussion points to achieve the goal of providing recommendations to DPHHS regarding the statutory charge in accordance with Title 53-19-403.
- 3. A quorum of the Task Force is seven members, including conference call participation of members. The Task Force will <u>seek</u> consensus on recommendations. The Task Force understands that, while it will use an agreement-building <u>process</u>, the work of the Task Force may or may not result in a consensus <u>outcome</u>. For this work, consensus is defined as: when at least a quorum of seven of the Task Force members is present, and all members present can say they <u>support</u> the group's procedural decision at hand. "Support" means that all of the members can state that they agree, or are neutral (implies they will let the issue pass). If members disagree they will be expected to suggest a way to move past the impasse or package the option so that it will be acceptable and meet the member's interest. Prior to a meeting where consensus would be sought, a member who must be absent can submit written concerns that will be discussed at the meeting before a decision is made.
- 4. Fallback: when and if the Task Force has tried in good faith, but is still unable to reach consensus, the fallback is to report a brief summary description of majority and minority points of agreement and disagreement, and then move on.

 Meetings are open, public, and observers and reporters are welcome. Meetings will not be run like public hearings and time will be set aside to take "public comment."

- The group will manage its time through the department coordinator and the facilitator in an open, flexible, yet focused way to accomplish the goals of the Task Force process, and in light of the numbers of people who are interested in attending or contributing, and the tasks at hand.
- 5. Task Force members may solicit public comment, verbal and written, on their own, between Task Force meetings to better understand the range of issues and perspectives Montanans have related to Universal Newborn Hearing Screening and Intervention Task Force.
- 6. Meetings will begin and end on time.
- 7. Short <u>summaries</u> of meeting outcomes will be prepared by the facilitator within one to two weeks after each meeting and posted on http://www.dphhs.state.mt.gov. At a minimum, a compilation of Task Force points of agreement and disagreement will be prepared in report form and given to DPHHS after March 15, 2006.

10.0 Neutral Facilitation

- 1. The Montana Consensus Council was asked by DPHHS to serve as the neutral facilitator for this Task Force. MCC is impartial and nonpartisan; it is not an advocate for any particular interest or outcome.
- 2. The facilitator's role in this case, includes, but is not limited to:
- Help the decision makers and participants design a practical, useful set of recommendations.
- Serve as an independent <u>process</u> manager with responsibility to the Task Force and the public at large (see MCC's Professional Code of Conduct in Appendix B).
- Help Task Force develop agendas and materials in advance of each meeting.
- Be the Task Force's scribe to record areas of agreement, areas of disagreement and strategies for implementation.

11.0 Media Relations

- 1. The main media contact will be Gayle Shirley, the Public Information Officer of DPHHS. Requests from the media for comments or interviews will be directed to Gayle Shirley.
- 2. Meeting results will be recapped at the end of each meeting so the understanding of outcomes is uniform.

12.0 Participation in This Public Process

- 1. The Task Force process is a key <u>supplement</u>, <u>not a replacement</u>, for agency analysis and decision-making by the Governor, DPHHS, and the Montana Legislature.
- 2. The appointees will seek out the perspectives of a wide range of their like-minded peers in related organizations with a stake in outcomes of policy changes relevant to UNHSI.
- 3. The Task Force will accommodate people with disabilities by accepting input through alternative formats.

13.0 Task Force Protocols

- 1 Use this Task Force as the primary place to develop recommendations in accordance with Title 53-19-401.
- 2 Give freely of your experience.
- 3 Confine your discussion to the topic.
- 4 Say what you think.
- 5 No discounting what people bring forward/no personal attacks.
- 6 Only one person should talk at a time.
- 7 Seek to understand the other person's point of view.
- 8 Help create and ensure the success of the outcome.
- 9 Build on others' ideas.
- 10 Keep a sense of humor.
- 11 Help the facilitator help the <u>Task Force get to useable results</u>.
- 12 Call for a break anytime it is needed.
- 13 Avoid side conversations when someone is speaking.
- 14 Establish ground rules for conference calls (provided by Evelyn Rider).

14.0 Conference Call Protocols

- 1. Take time to familiarize yourself with the equipment prior to the start of the meeting.
- 2. Keep your site muted except when talking.
- 3. Introduce yourself and your site.
- 4. Go site by site for discussion.
- 5. Allow each individual to complete comments.
- 6. Summarize major points and tasks assigned to specific individuals.
- 7. Begin planning for the next meeting.

APPENDIX

UNIVERSAL NEWBORN HEARING SCREENING AND INTERVENTION ADVISORY GROUP (THE TASK FORCE)

Members (Limited by law to 12)

Betty Van Tighem – Deaf Adult

Cleo Klepzig – Parent of Deaf Child

Evelyn Rider, M.D., Director of Benefis East Newborn Intensive Care Unit

Laura Nicholson, M.D., Pediatrician (AAP)

Vicki Strohmayer, Holy Rosary Hospital

Doug Baldwin, Audiologist

Kristen Kober, Audiologist, Billings Area Indian Health Service

Marilyn Pearson – Office of Public Instruction

Jackie Forba- Children's Special Health Services (CSHS) program

Erica Swanson – Part C of IDEA

Sandy McGennis – Outreach, Montana School for the Deaf and Blind

Melissa Ann Hansen – Parents, Let's Unite for Kids (PLUK)

Consultants (non-voting)

Kitty Griffin, Speech Pathologist

Lynne Koester, PhD – Developmental Psychologist

Casey Blumenthal, RN – Montana Hospital Association

Frank Malek, Medicaid, MT Dept of Public Health and Human Services

Sib Clack, UNHSI Monitoring Program, FCHB, PHSD, DPHHS Steve Gettel, MSDB

BJ Archambault, Children's Special Health Services (CSHS) program

Marylynn Donnelly (substituting for Jackie Forba on Task Force),

Children's Special Health Services (CSHS) program

12/23/2005

Code of Professional Conduct

Montana Consensus Council Executive Policy 1 Originally adopted in 1994

Most Recently Revised July 2003

Statement of Policy

The Montana Consensus Council is a public-private partnership attached to the Department of Administration for administrative purposes. We are committed to the following roles and responsibilities during any and all public participation, collaborative problem solving, and/or consensus-building processes that we help design and manage.

Responsibility to the Participants

1.1 Impartiality

The Council is nonpartisan. It is not an advocate for any particular interest or outcome. We seek to be impartial -- that is, it is free from favoritism or bias either by word or action -- and are committed to serving all parties rather than a single party.

1.2 Appropriateness of Public Processes

The Council provides information to potential participants on a range of processes to foster public dialogue, citizen participation, agreement building, and dispute resolution. The Council does not believe that there is one and only one right way to proceed. We tailor each public process to the needs and interests of the participants.

1.3 Conflicts of Interest

The Council does not enter or continue in any process if it believes that participation would create a conflict of interest or raise a substantial question as to its impartiality. The Council will disclose any conflict of interest to all the participants, whenever it appears during the process.

1.4 Scope of Work

Before committing to work on a public process, the Council insists that the participants and the Council agree on the specific services to be provided by the Council, a strategy and timetable for beginning and ending the project, and the nature of compensation to the Council.

The Council will not participate in any process where the purpose and expectations are not clear to all participants. The Council will withdraw from any process if its continuing involvement is not acceptable to the participants.

Responsibility for the Process

1.5 Process Design

The Council works with all the participants to design an appropriate public process. Given our commitment to helping citizens and officials implement effective solutions to public problems, we encourage potential participants to err on the side of including more rather than fewer stakeholders.

1.6 Training Participants

Prior to convening any public process, the Council believes in offering appropriate negotiation, consensus building, and other training to all participants (together).

1.7 Facilitation and Mediation

The Council may engage in a variety of activities to coordinate a project. It will serve as a impartial facilitator during meetings; focus the energy of the group on a common task; protect individuals and their ideas from attack; encourage everyone to participate and share their ideas; help the group find mutual gain solutions; coordinate pre- and post-meeting logistics; and, where necessary, shuttle among the participants between meetings. The Council will also help the participants amend an agreement during the implementation process. The Council will enforce the ground rules agreed to by the participants and confront any participant when the Council believes the participant is not acting in good faith and is inhibiting the group from moving forward.

In appropriate circumstances, the Council may refer the participants to other facilitators or mediators for assistance.

1.8 Team Approach

The Council prefers to work in teams to ensure that we effectively coordinate the project.

1.9 Confidentiality

The Council respects the confidentiality of private communications with any of the participants.

1.10 Documentation

Unless otherwise agreed to by all the participants and the Council, the Council shall prepare and maintain an objective record of the public process, including areas of agreement, disagreement, and strategies for implementation. The Council shall prepare both draft and final documents, and when appropriate, research reports.

1.11 Implementation

The Council will continue to provide consultation to the participants during the process of implementing any agreement.

Responsibility to the Public

1.12 Unrepresented Interests

The Council contributes to the integrity of the process by identifying unrepresented interests during the building or implementation of any agreement.

Commitment to Improve Services

1.13 Training and Education

The Council constantly upgrades its skills through formal education, training programs, workshops, practical experience, and research and publication.

1.14 Evaluation by Participants

In an effort to improve our services and share the lessons learned, we encourage participant to provide candid comments and suggestions about the process, its outcomes, and our performance.